

Quality Improvement in Healthcare: A Focus on Patient Focused Strategies

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Abstract

Health care challenges, such as high prevalence of chronic illness, increasing costs, decreasing resources, rising patient expectations and more complex care episodes, have exposed the inadequacy of the traditional paternalistic approach to quality improvement. Policy makers increasingly believe that the ability to improve the quality of care and control costs will require an effective partnership with informed and engaged patients. Thus, current health systems are shifting toward consumer-centric quality improvement approach, by empowering patients to play a more active role in the planning and delivery of health services. This paper provides knowledge about improving the quality of health care through patient focused strategies. Patient-focused strategies consider the care user as the center for change, or contributing to change into the desired outcome. Strategies to encourage patients to play a more active role in their health care are classified by interventions designed to improve: health literacy, shared decision-making, self-management/self-care, patient safety, access to medical advice, and patient experience of care. The paper focuses, more specifically, on interventions designed to improve self-management and patient experience of care. Given the high-level political commitment to patient empowerment, and the increasing recognition that a high quality health service is the one organized around and responsive to the needs of the people using, the area of patient-focused strategies is likely to receive even greater attention in the future. The research community therefore needs to explore various ways of using patient-focused interventions more effectively in quality improvement at both an individual and a collective level.

Keywords

Quality improvement, patient-focused strategies, patient-centered care, self-management, patient experience, healthcare

Introduction

Since the US Institute of Medicine's landmark reports, To Err Is Human (2000) and Crossing the Quality Chasm (2001), revealed widespread incidence of medical errors in US hospitals, there has been a great deal of effort to measure and improve the quality of care across a wide range of countries and health care systems [1]. An increased number of both private and public health care organizations are striving to improve quality

in health care. Organizations such as the Institute for Health Care Improvement (USA), the Picker Institute (Europe), the European Observatory on Health Systems, and the Health Foundation (UK) among others are aiding the improvement of care and health care industry services. For example, the 'always event' (AE) developed by the Picker Institute is being implemented across health care systems to offer a clear, action-oriented set of behaviors that improve health

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outcomes [2]. In addition, medical associations and medical specialties within health care are influencing quality improvement by providing treatment recommendations and setting standards for professionals and health organizations to use when treating patients. These organizations, alongside health policy makers, are helping to mold the current health care industry quality improvement efforts [3].

Quality in health care is defined in many ways by different health care systems. One of the most widely accepted definitions is that of the US Institute of Medicine, where quality is defined as the "*degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge*"[4]. Care with high quality is characterized as one that is safe, knowledge-based, effective, efficient, equal and focused on the patient [5, 4]. Health care quality is also defined along technical and functional dimensions [6]. Technical quality is the service delivered (skill and expertise), while functional quality indicates how this service is delivered (interactions) [7].

Improving quality is about safeguarding the safety, effectiveness, patient centeredness, timeliness, efficiency and equity of health care [8]. Even though the idea of quality improvement in health care is often referred to as an emerging science of improvement [9], efforts to develop and improve quality started almost at the same time as medicine itself. Historically, physicians have aimed at developing better and safer care and treatment approaches for patients. However,

the modern era of quality improvement started with the 1966 publication of a paper by Avedis Donabedian, in which he examines the evaluation of the quality of medical care. One of the many interesting ideas proposed in this paper is that assessing quality medical care requires the evaluation of three elements: structure, process, and outcome [7]. The evaluation of structure examines the accessibility, availability and quality of resources, such as bed capacity of a hospital, health insurance and number of nurses with advanced training. Process evaluation assesses the delivery of health services by care providers, such as using guidelines for care of diabetic patients. Outcome assessment measures the final result of health care. Examples include mortality, patient satisfaction and improved health status [7].

In the 1980s, health care leaders borrowed techniques from the groundbreaking works of Edward Deming (termed as the "14 Points of Management"), that helped in rebuilding the manufacturing businesses of post-World War II Japan [9]. Deming, known as the father of Total Quality Management (TQM), promoted "consistency of purpose" and systematic analysis and measurement of process steps relative to capacity or outcomes [10]. As an organizational approach, TQM uses organizational management, teamwork, systems thinking, defined processes and change to create an environment for improvement. This approach incorporates the view that the entire organization must be committed to quality improvement to achieve the best result (a whole system approach) [11].

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In the health care industry, continuous quality improvement (CQI) is used interchangeably with TQM. CQI, which is based on the principle that there is an opportunity for improvement in every process and on every occasion [12], has been used widely in developing clinical practice [13]. Besides TQM/CQI, other quality improvement strategies such as: International Organization for Standardization ISO 9000, Zero Defects, Six Sigma, Plan-Do-Study-Act (PDSA), and Toyota Production System/Lean Production among others, have been proposed for improving clinical practice [14,15].

Traditionally, health care has focused on quality assurance and quality control [14], with improvement works largely centered on regulation (e.g. licensure, accreditation, credentialing, certification etc.) [16], incentives (both monetary and non-monetary rewards) [17], competition, organizational and managerial processes [18], and health care delivery models [19]. The traditional role of patients has been to provide information to health care professionals about their health conditions, treatment preferences and physical bodies [20].

There is growing evidence that quality improvement efforts are making a positive impact on the health care industry [3]. However, as patients' expectations rise, patient care becomes more complex, and resources continue to shrink, policy makers are finding that traditional approaches to improving health care quality are no longer adequate [21,22]. Moreover, the current shift

in disease patterns from acute to chronic illnesses and the accompanying need for patients to engage in long-term self-care activities has necessitated health care systems to refocus their approaches to quality management [23,24]. The paternalistic approach, which views the provider as "expert" and the patient as "passive recipient" of medical care is ineffective at treating long-term conditions that require daily management by patients and their caregivers [24].

Current health policy aims at strengthening the role of patients in health care. The ability of health care systems to improve the quality of care and control costs will require an effective partnership with informed and engaged patients [25,26]. Policy makers increasingly believe that patients can play a number of roles in health care to improve quality and reduce costs [27].

Hibbard [28] identifies three roles of the patient in health care quality improvement: the informed choice role, the co-producer role and the evaluator role. The informed choice role refers to patients' use of comparative performance data to select high performing providers, hospitals or nursing homes for themselves and their family members [29]. As co-producers, patients engage in effective self-care, take preventive actions, and collaborate with providers to define and implement care plans [30]. Assuming this role, [31] describe patients as "co-creators of value during care". Patients take on the evaluator role when they act as the source of data on provider and performance, and when

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they participate in defining the parameters of quality [32].

When patients take on the informed choice role, the co-producer role and the evaluator role, they are able to secure better care for themselves and also contribute to mechanisms that improve the quality of care [28]. Thus, a range of patient-focused interventions have been developed across health care systems, with the aim of supporting patients and their caregivers to play a more active role in health care quality improvement.

Study aim

The purpose of this paper, therefore, is to use information from the extant literature, in the form of a narrative review, to provide knowledge about quality improvement in health care through patient focused strategies. The paper focuses, more specifically, on interventions designed to improve self-management and patient experience of care.

A non-systematic (narrative) search was conducted to collect the necessary information for this study. Electronic databases such as Google Scholar, PubMed, Scopus and Science Direct were searched for studies on patient focused quality improvement strategies. Keywords such as: "quality improvement in healthcare", "patient-focused quality improvement strategies", "self-management", and "patient experience" were used in the narrative search strategy.

The rest of the paper is structured as follows: first, we provide a description of the existing patient-focused quality improvement strategies; we then narrow the work to focus on self-management and patient experience of care, two key patient-focused quality improvement strategies; the final part is a conclusion with recommendations for policy, practice and research.

Patient-Focused Quality Improvement Strategies

Traditionally, health care delivery has been based on the biomedical model of medicine, which regards the patient as a disease-carrier requiring diagnosis and treatment [33]. As an alternative to this disease centered approach to health care, the biopsychosocial model [34] was introduced in 1977. The biopsychosocial model is a comprehensive, systems approach to health, where physical, psychological and environmental elements interact to contribute to an individual's health. Patients are considered as proactive agents in promoting positive health outcomes, rather than as passive recipients of care as regarded by the traditional biomedical model [35].

Ensuring that people are involved in and central to the health care process is now recognized as a key component of services planning and development [36]. Terms such as 'patient public involvement', 'user involvement', 'patient-centered care' person-centered medicine' and 'co-design' are commonplace in health policy systems [37]. Focusing care on the patient is one of the six aims of the US Institute of Medicine's Health Care Quality Initiative [4]. According to Berwick [38], good quality care is the one

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delivered in such a way that content and form are in line with the values and preferences of patients. Classical theory in quality management and improvement also considers patient (customer) focus as one of the key principles, alongside process orientation, teamwork and decisions based on facts [39].

The importance of patients as active participants in health care delivery is recognized in various models of care. For instance, the Chronic Care Model [40] and the Patient-Centered Medical Home [41] emphasize the vital role of patient-focused strategies in the process of delivering high quality care.

Patient-focused strategies are defined as strategies that recognize the role and contribution of patients as active participants in the process of securing appropriate, effective, and responsive health care at an individual and collective level [25]. The patient is considered as the center for change, or contributing to change into the desired outcome [42]. Strategies may be targeted at the decision to seek professional care (e.g. provision of information to help patients make decisions about whether or not to seek health care, and if seeking care, which care provider to attend), at contacts with health care providers (e.g. strategies to support and prepare patients to participate actively during clinical encounters), or at patients after care has been provided (e.g. feedback by means of reporting care experiences, complaints or comments to aid service improvement) [37,42].

Interventions to encourage patients to play a more active role in their health care are based on the concept of patient empowerment. The idea of empowerment is rooted in the social action ideology of the 1960s and the self-help perspectives of the 1970s [43]. It emphasizes rights and abilities rather than deficits and needs of individuals [44]. Nutbeam [45] defines patient empowerment as "*the process where people gain greater control over decisions affecting their health*". The principle is to enable patients to become primary decision makers in managing their ill health, based on the notion that patients are more motivated to initiate and sustain behavioral changes of their choice than changes prescribed by others [46]. An empowerment-based approach therefore seeks to reinforce some general abilities in people, such as the ability to identify needs and psychosocial problems, determine personal goals, devise strategies to attain these self-selected goals, solve problems, and manage stress and cope with emotions [47].

Patient-focused strategies are classified by interventions designed to improve: health literacy, shared decision-making, self-management/self-care, patient safety, access to medical advice, and patient experience of care (Figure 1) [25,16].

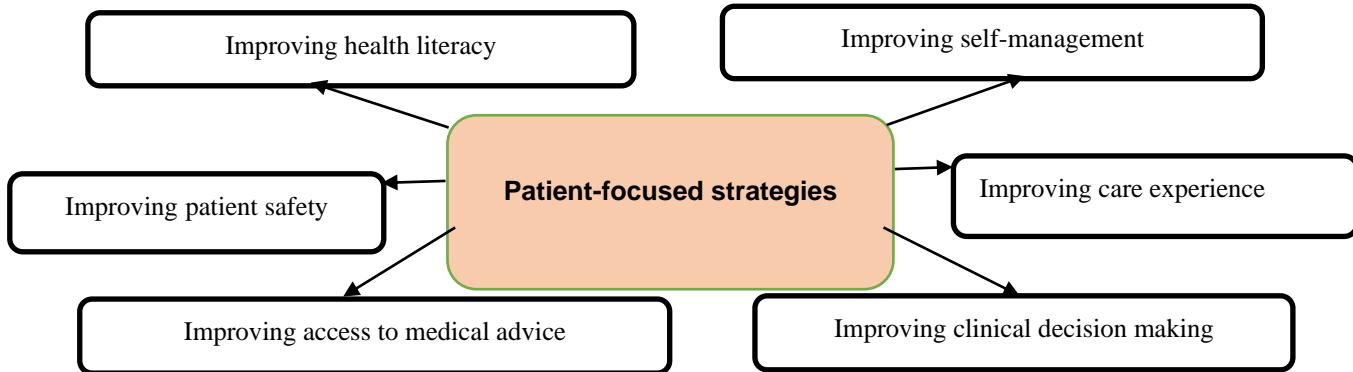
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Figure 1. Goals of patient-focused quality improvement strategies (adapted from Coulter & Ellins [25])

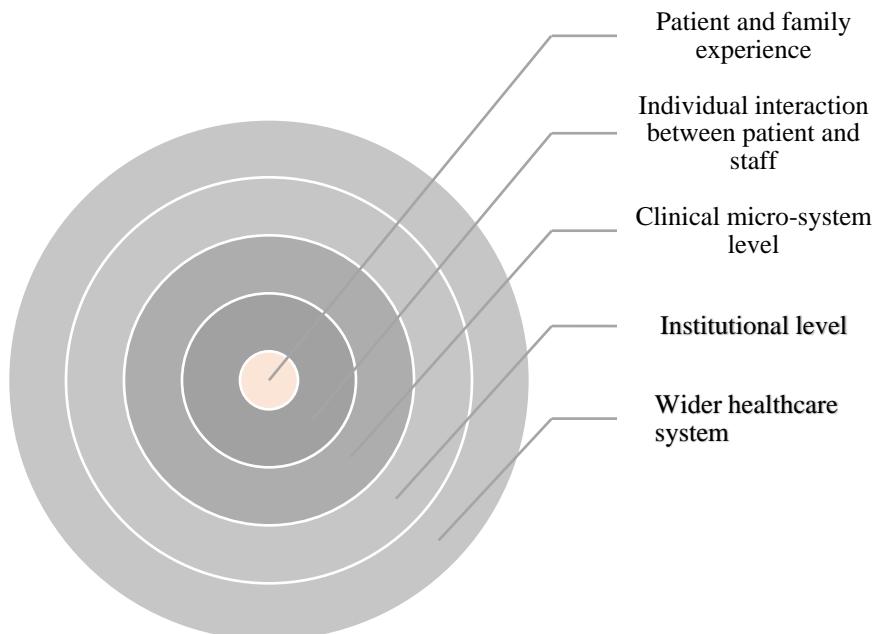


Figure 2. A Framework for the analysis of factors influencing patient experience (adapted from Cornwell and Goodrich, 2009)

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Improving health literacy involves enabling patients to read, understand, evaluate and use health information to make appropriate decisions about health and health care [48]. Health literacy interventions have three key objectives: to provide information and education, to encourage appropriate and effective use of health resources, and to tackle health inequalities [16]. Interventions take a number of forms such as: written health information tailored to an individual patient's needs; computer-based information; interactive television, audio tapes, and web-based interventions; and information and education addressed specifically to people with low levels of health literacy [25].

In clinical decision making, clinicians and patients work together as active partners to clarify acceptable medical options and choose appropriate treatments [49]. Patient coaching and question prompts are used to empower patients to take a more active role in consultations. Evidence-based patient decision aids are also used to facilitate the process of making informed decisions about disease management and treatment [16].

Self-management strategies seek to empower patients to recognize, treat, and manage their own health problems, independently of the medical system [48]. Research indicates that individuals and families provide a far greater quantity of health care (about 85%) than do health professionals [50]. For instance, an assessment by the UK Department of Health shows that people with diabetes have on average about three hours contact with a care provider and do self-care for the remaining 8,757 hours in a year [51]. Hence,

supporting self-management is key to delivering quality health care.

The recognition of patients' role in improving the safety of their care is recent, as research into it is still in its early stages [52]. Nonetheless, some strategies, though not many, have been devised to enable patients to partner more effectively with care providers to reduce medical errors and improve safety. They include: interventions encouraging patients to participate in infection control initiatives, such as hand hygiene; providing information to aid patients to choose safe providers; enhancing patient adherence to treatment regimens; and initiatives encouraging patient direct reporting of adverse drug events [25].

Feedback on professional performance and care delivery is seen as a means of stimulating quality improvement [42]. After a contact with a care provider or health care organization, patients can reflect on the care they have received. Their experiences and evaluations can be fed back to health care workers and organizations, and this may serve as the basis for service improvement (Hibbard, 2004). Feedback from patients can be obtained through patient surveys (e.g. patient experience surveys, satisfaction surveys, etc.), provider choice and complaints [25].

Access deals with the availability, utilization, relevance, effectiveness, acceptability, and equity of health services [53]. Initiatives to improve access are broadly categorized into absolute and relative strategies. Absolute strategies seek to increase the overall

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availability of services, while relative strategies aim at reducing inequalities and improving fairness [54]. Initiatives such as: new models of professional-patient communication, remote teleconsultation, walk-in centers, and outreach clinics have been (and are being) implemented to improve patients' access to medical advice [25].

Even though patient-focused strategies vary in terms of their implementation approaches, the ultimate aim of all of them is to place patients at the center of improvement efforts by empowering them to play the informed choice, the co-producer, and the evaluator roles Hibbard [28] in the process of care delivery. For instance, patients need high levels of health literacy to perform the informed choice role; skills in both clinical decision making and self-management, combined with high levels of health literacy empower patients to assume the co-producer role; whereas care experience strategies facilitate patients' role in care evaluation.

Self-management and patient experience, the two main areas of focus in this chapter, are discussed in detail in the sections that follow.

Self-management and the chronic disease epidemic

Chronic diseases have become a primary concern for health care systems worldwide. The World Health Organization (WHO) states that about 70% of all deaths worldwide are due to chronic conditions [55]. In 2008 alone, chronic diseases such as heart disease, diabetes and chronic obstructive pulmonary disease were responsible for 36 million deaths worldwide [56]. Projections are that chronic conditions will account for 60% and

70% of the global disease burden by 2020 and 2035 respectively [57,56]. Chronically ill patients are frequent and long term users of health services. The evidence suggests that about two-thirds of patient encounters with health professionals are for the management of chronic conditions [58]. Resources are increasingly being diverted to the care of chronic diseases, with little effect on reducing the burden on both health systems and patients' quality of life [59]. In the United States for instance, the economic burden of chronic illness is around 78% of the country's total health care spending [60]. This growing burden of chronic illness highlights the limitations of approaching chronic disease care purely from the perspective of the medical model that focuses on the disease rather than the person with the disease [25]. One approach highlighted as effective in reducing the impact of chronic disease and improving the quality of life of people with long-term health conditions is support for self-management [61,62]. The US Institute of Medicine's report titled "Priority Concerns for National Action: Transforming Health Care Quality" identified self-management as one of the most urgent areas of concern for providing quality health care within the United States' health care system [63]. The report indicates that self-management is a vital tool for the management of chronic illness. Similarly, a report by the World Health Organization (WHO) strongly supports the implementation of self-management strategies to empower chronically ill patients to manage their health [48].

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Moreover, in a Robert Wood Johnson Foundation report titled “Essential Elements of Self-Management Interventions” [64], Lorig and Holman [65] identified five core self-management skills that could be tailored to individual patients to improve health care quality: decision-making, problem solving, resource utilization, formation of a patient-provider partnership, and adoption of actions to manage health and related conditions [65]. The concept of self-management carries a message of control, empowerment and confidence for people with chronic illness [66].

Goldstein [67] defines support for self-management as “*a patient-centered collaborative approach to care to promote patient activation, education and empowerment*”. The whole concept is based on three key assumptions: 1) people with chronic conditions are the experts in managing their lives; 2) health professionals have expert knowledge about patients’ conditions; and 3) best outcomes are achieved when health professionals work in partnership with patients and caregivers to manage their chronic conditions [61].

Self-management skill development and support is a key component of Wagner’s Chronic Care Model (CCM), one of the most influential models of chronic disease management. The model emphasizes the need to train and support patients to become active agents in their own health. According to Wagner [68], chronic disease is better managed by productive interactions between patients and their clinical health teams, within settings that utilize reliable, evidence-

based approaches to self-management [68]. Within the CCM, six key elements for better chronic disease management are identified: 1) delivery system design, 2) decision support, 3) clinical information systems, 4) community resources and policies, 5) health care organizations, and 6) self-management [68].

Bandura’s self-efficacy theory [69] is a major theoretical underpinning of self-management. Self-efficacy refers to people’s belief in their ability to successfully learn and perform a specific task or behavior [48]. A strong sense of self-efficacy leads to self-control and people’s willingness to take on new and difficult tasks. When applied to the concept of self-management, the theory suggests that patients are empowered and motivated to manage their conditions when they are confident in their ability to attain their goals (perceived self-efficacy) [48]. Lorig and Holman [65] also provide a conceptualization of self-management. The authors assert that for those with chronic disease, “self-management is a life-long task” and “only the patient can be responsible for the day-to-day care over the length of the illness” (Lorig and Holman, 2003, p. 1) [65].

Various self-management strategies to support chronically ill patients optimize the management of their health have been developed and implemented. These have varying levels of intensity and differences in content [70]. However, according to Lorig and Holman [65], self-management support interventions have a common goal of enabling patients to perform three sets of tasks: managing their health conditions

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medically (e.g. taking medication or adhering to a special diet, self-monitoring of blood sugar, etc.); carrying out normal roles and activities; and managing the emotional aspects of their illness.

Battersby and colleagues at Flinders Human Behavior and Health Research Unit (FHBHRU) have identified six key principles of self-management:

- a. Knowing and understanding one's condition;
- b. Monitoring and managing signs and symptoms of one's condition;
- c. Actively sharing in decision-making with health professionals;
- d. Adopting lifestyles that promote health;
- e. Managing the impact of the condition on one's physical, emotional and social life; and
- f. Following treatment plan agreed with one's health provider [71].

Examples of self-management support interventions include: ongoing monitoring/support, facilitating patient access to personal medical information, self-management education, self-help and support groups, and patient-centered telecare [25]. Of all the interventions, self-management education is the most common and well-known. Evidence also indicates that self-management education is the most effective strategy for improving self-care abilities of patients with long-term and chronic illness [72,143].

The link between self-management and health care quality

The philosophical assumptions underpinning the implementation of self-management support interventions are that they will improve well-being and clinical outcomes, strengthen self-determination and participation in health care, and reduce health care utilization and health care costs [73]. There is strong evidence across studies that self-management programs have positive effects on physical and emotional outcomes, and related quality of life. The interventions consistently result in greater energy and reduced fatigue [74], fewer role limitations [75], better psychological well-being [76], enhanced partnerships with physicians [65], improved health status [77], greater self-efficacy, and reductions in pain and symptoms [78]. A study by Namarata and colleagues has confirmed these earlier findings. The authors conducted a quasi-experimental pre-post study to evaluate the effectiveness of a self-management support intervention in Singapore. Participants reported less pain ($p = 0.03$) and shortness of breath ($p = 0.02$), as well as general improvements in self-reported health ($p = 0.02$) and quality of life ($p = 0.01$) [79].

There is also evidence that self-management support programs reduce health care utilization. For instance, a randomized community based outcome trial by [80] revealed that patients who participated in the self-management program had fewer emergency room visits. A meta-analysis of generic programs [74] showed a significant reduction in the number of hospitalization days. Finally, a review of professionally-led self-management programs for patients with chronic obstructive pulmonary disease found

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that the programs were associated with a reduction in the rate of hospital admissions [81].

Some studies have, however, shown little or no positive impact of self-management interventions. For instance, a randomized controlled trial (RCT) of self-management training for patients with multiple chronic conditions did not show positive effect on patients' self-efficacy [82]. Similarly, an RCT by Adolfsson [83] did not find significant drops in patients' glycated hemoglobin (HbA1c) levels. Other studies found no positive impact on osteoarthritis [84], hyperlipidemia and asthma [85]. Further, evidence on the effects of self-management interventions on health services use is sometimes moderate [86].

Although not all interventions and studies report statistically significant results, the underlying trend still supports improved health outcomes for chronically ill patients [74]. Available evidence also shows that the impact of self-management strategies often results in more appropriate utilization of health care resources and consequently reduce health care costs [87].

Self-management education as an intervention to improve patient self-care behaviors

Self-management education (SME) is the process of teaching persons with chronic disease to manage their illness and treatment by providing them with the knowledge and skills that are needed to perform self-care behaviors, manage crises, and make lifestyle changes [88]. Promoting self-management

through education is in line with the World Health Organization (WHO)'s best practice strategy for chronic conditions, which is to "educate and support patients to manage their conditions as much as possible" [89]. Educational programs involve a variety of psychological and behavioral interventions; and a combination of didactic, interactive and collaborative teaching methods tailored to patient's specific needs [90]. Content of education could be general (applicable to several chronic conditions) or specific to a condition (e.g. diabetes, asthma, hypertension, etc.). Educational sessions may be held in health care settings, in the community, or at home. Delivery mode may include individual, group, or self-mediated, and may be led by lay leaders, physicians, dietitians, nurses, or other specialists [70].

Subjects covered in educational programs include: relaxation and fatigue symptom management, problem solving; managing depression; making informed treatment decisions; managing medication; cognitive skills; anger, fear and frustration management; communication skills; the role of healthy eating and exercise; planning for the future and making an action plan; and working in partnership with health care providers [91].

SME is often considered an aspect of patient education. However, the two activities can be distinguished from one another. Patient education focuses on delivering knowledge and skills to patients to enable them follow medical advice. SME, on the other hand, is concerned with empowering patients to take active control of their illness and apply

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problem-solving skills to meet new challenges [25]. Bodenheimer and colleagues provide a detailed comparison between the

two educational activities using six factors (see Table 1):

Table 1: Difference between traditional patient education and self-management education

	Traditional patient education	Self-management education
Education (what is taught)	Information and technical skills about the disease	Skills on how to act on the problem
How problems are formulated	Problems reflect the inadequate control of the disease	The patient identifies the problems she/he experiences that may or may not relate to the disease
Relation of education to the disease	Disease is education specific and teaches information and technical skills related to the disease	Education provides problem solving skills that are relevant to the consequences of chronic diseases in general
Theory underlying education	Disease specific knowledge creates behavior change, which in turn produces better clinical outcomes	Self-efficacy (greater patient confidence in his/her capacity to make life-improving changes) yields better clinical outcomes
Goal of education	Compliance with the behavior change taught to the patient to improve clinical outcomes	Increased self-efficacy to improve clinical outcomes
The educator	A health professional	A health professional, peer leader or other patients

(Source, Bodenheimer et al, 2002)

Self-management education models

Several models (both generic and disease specific) have been developed to promote education in self-management. However, the majority of the educational programs are based on the Stanford Model, the Expert Patient Program, and the Flinders Model. Developed by Stanford University in the United States of America, the Stanford Model is based on the premise that chronic patients have similar concerns, are capable of managing aspects of their conditions, and

will have better outcomes with specific skills and training [74]. The program, which is based on Bandura's self-efficacy theory, is a standardized 6-week group education, and uses peer educators as instructors [75]. The Expert Patient Program, a UK adapted version of the Stanford Model, seeks to promote the knowledge, skills and confidence needed by patients to manage their chronic conditions through training and support from professionals, such as nurses [92]. The Flinders Model promotes the role of care providers in building self-efficacy skills with

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patients, and actively engaging patients in using these skills during provider-patient interactions. It is a one-on-one model based on cognitive behavioral therapy (CBT) principles [93].

Researchers have been investigating factors that could influence the effectiveness of SME interventions to aid policy makers implement more cost effective educational programs. Intervention attributes such as: mode of delivery (group sessions versus individual teaching), delivery setting (community gathering places, health centers, etc.), program duration, and trainer's background (medical, allied health or peer) have been investigated [94,95,96,97,98]. Evidence shows that group sessions are more effective than do individual teachings [97,98], and group education sessions offered in community gathering places show more positive effect than those offered at health centers [98]. Evidence also indicates that program duration does not appear to change interventions' effectiveness [95].

Other studies have examined personal characteristics of patients, such as: health status [99,100,101]; disease duration [102]; age, educational level, and partner's influence [103,104]; economic status [105]; language and culture [106]; and gender difference [107,108,102]. Individual health status such as: co-morbidities, illness severity, symptoms, side effects from treatment and cognitive functioning are cited as factors that influence the effectiveness of SME interventions [101]. For example, shortness of breath from chronic obstructive pulmonary disease could contribute to one's inability to

exercise as part of a self-management intervention [100]. While SME appears to work better for older people and individuals with high educational status [103], gender difference has not been found to influence interventions' effectiveness [108]. Research also suggests that people who experience longer disease duration before participating in an SME intervention often show less positive improvements in both behavioral and biomedical outcomes compared with the more recently diagnosed patients [102].

Finally, the quality with which SEM intervention is implemented has been considered as a determining factor of program effectiveness [109]. A key element of the quality of program implementation is its fidelity, defined as the degree to which the intervention is delivered as planned [110]. Participants in interventions where fidelity requirements are met largely experience improvements in self-efficacy and related quality of life [111].

Patient experience of care

To live up to the widespread health care notion of "nothing about me without me" [112], it is important to understand the current experience of patients and partner with them to drive improvement efforts [113]. Lessons from approaches to customer experience by other industries can be of great use to health care organizations. Listening to customers to improve service provision indicates that the service values feedback about the user's experience. The move away from the industrial economy view of the product as a service outcome to a modern view that what a customer receives at the end of a service

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encounter is the actual experience, has been considered fundamental to the rise of patient experience in health care [113]. This Experience Economy suggests that organizations should create a more engaging and personal experience with customers/users [114].

While clinicians may feel they have a good understanding of their patients' needs, research suggests there is often a mismatch between the views and concerns of professionals and that of patients [115,116]. Thus, it is imperative to establish what constitutes quality of care from the perspective of both patients and health professionals [117]. Monitoring patient experience is essential for improving service quality, stimulating innovation in the redesign and delivery of care, improving accountability and building patient-centered approach to care delivery into health care organizations [118]. It is considered part of a wider trend towards a more bottom-up approach to service planning and provision [119].

Patient experience as a concept in quality improvement

Patient experience is a measure of patient centeredness [4]. It is conceptualized as users' lived experiences of care, and as feedback received from users regarding these experiences [120]. The World Health Organization (WHO) uses the term "responsiveness" to refer to a measure of patient experience of a health care system. The responsiveness of a health care system is determined by eight key indicators: autonomy, choice, communication,

confidentiality, dignity, prompt attention, quality of basic amenities, and support (access to family and community support networks) [121].

Patient experience is regarded by health care policy frameworks in many countries as a core component of health care quality, alongside clinical effectiveness and patient safety [122]. The National Health Service (NHS) of England was among the pioneers to mandate a national patient survey in 2001, followed by the USA with its national Hospital Consumer Assessment of Healthcare Providers and Systems Survey (HCAHPS). Australia, Canada, New Zealand and many European countries now use measures of patient experience and have made systematic arrangements for measuring and monitoring patients' views at the national level [123]. A study of quality improvement (QI) strategies in Europe revealed that monitoring patients' views by systematically conducting patient surveys was common among 64.5% of 389 European hospitals surveyed [124].

Dimensions of patient experience

From the early 1990s, a number of generic frameworks that aim to capture key dimensions of patient experiences have been developed [125]. Key among them are the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Survey¹, which has eight dimensions of patient experience; the Institute of Medicine Framework², with nine domains; and the Picker Principles³, consisting of seven general quality aspects that patients consider essential within health care. More recently, Staniszewska and colleagues developed the

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Warwick Patient Experiences Framework (WaPEF)⁴ based on earlier frameworks and clinical guidelines [126]. Other recently defined patient experience dimensions include the work of Shale [127] that categorizes patient experience into three dimensions: physiologic illness experience, customer service (not satisfaction), and lived experience of illness; and that of Hewitson [128] which defines patient experience as: staff-patient interaction, information provision, involvement in decisions, and support for self-care.⁵

All of these frameworks are related with significant overlapping elements, which could be classified into either relational or functional aspects of care [129,130]. Relational aspects refer to the interpersonal aspects of care such as empathy, respecting patients' preferences, involving patients and their caregivers in decision-making, and providing information to enable self-care [130]. Functional aspects relate to basic expectations about how care is delivered –

attention to physical needs, clean and safe environment, effective co-ordination between professionals, and timeliness of care [129]. Frameworks are adapted to suit a particular health care context, but it is important to ensure that assessment tools cover both the relational and the functional aspects for a comprehensive evaluation of patient experience of health care.

Methods of assessing patient experience

There are many different ways to assess patient experience of care. Most frequently, questionnaire surveys have been used in routine clinical practice. Surveys are most often administered on paper, either handed out to patients on-site or posted to them following attendance at a health care facility [120]. New development in technology has resulted in surveys being administered using other methods such as SMS messages to patients' phones, online surveys, and the use of handheld devices or kiosks to get real-time feedback [120]. Patient experience can also be assessed using interviews or focus groups

¹The CAHPS domains of patient experience: Communication with doctors, communication with nurses, responsiveness of the hospital staff, cleanliness of the hospital environment, quietness of the hospital environment, pain management, communication about medicines, discharge information [183].

²Patient experience dimensions defined under the Institute of Medicine Framework include: compassion, empathy and responsiveness, coordination and integration, information, communication and education, physical comfort, emotional support, relieving fear and anxiety, and involvement of family and friends (Institute of Medicine, 2001).

³The Picker Principles developed by the Picker Institute: Emotional support; physical comfort; information, communication and education; continuity and transition of care; coordination of care; involvement of family and friends; and access to care [131].

⁴The Warwick Patient Experiences Framework (WaPEF): Patient as active participant, responsiveness of services, an individualized approach, lived experience, continuity of care and relationships, communication, and information and support [126].

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[132]. Other sources of feedback on patient experience include: complaints and complements received by clinicians and feedback from patient groups [113]. These methods for assessing patient experience can be viewed along a continuum, from those that gather detailed descriptive feedback, often in qualitative form, to those that collect more numerical data [117]. Combining both qualitative and quantitative methods (mixed methods) presents an ideal way of providing the balance and specificity that improvement initiatives require [133]. For instance, while a survey may help in gaining feedback about general trends that can be quantified and traced over time; supplementing this with an in-depth interview may help in gaining a more detailed understanding of why patients feel a certain way [117].

Uses of patient experience feedback data

Patient experience feedback data could be used to inform improvement works by: either using the information to stimulate providers to improve service quality or physicians and administrators collecting and directly acting on the information to identify and remedy shortcomings in existing services [134,135]. Policy makers use patient experience data in a variety of ways to stimulate health professionals to improve service quality. These include: publicly disclosing performance data of individual health care organizations [136], using feedback data as the basis for accreditation and certification [125], and including patient experience surveys in pay for performance schemes [137]. Evidence however suggests that directly acting on patient data by organizations at the local level is the most effective way of

effecting change in the quality of health care [138,133,139].

Patient experience and patient satisfaction: conceptual differences and similarities

The development of reliable and valid patient feedback measures requires that the relationship between patient experience of care and patient satisfaction with a health care system is well understood. Patient experience and patient satisfaction are often used interchangeably, but conceptually, the two terms are different [140,141]. According to Sofaer and Firminger [142], overlooking the conceptual and methodological issues associated with the terms “experience” and “satisfaction” has reduced the value of much research.

Jenkinson and colleagues describe experience as a report of what occurred in a patient’s health encounter and satisfaction as their evaluation of that encounter [153]. Coulter [143] states satisfaction as the gap between a patient’s expectations and the actual care he/she has received. According to McMurray [144], the magnitude and direction of this gap is determined by the patient’s experience compared with his or her expectations, preferences and values. Patients’ expression of satisfaction with a service is therefore an assumption that they are happy after consuming it and that their expectations have been met [145].

Traditionally, patients’ views on health care performance have been sought through the measurement of patient satisfaction. However, satisfaction is often termed as an “ill-defined concept” which has been

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measured in many different ways [146,147,148]. With its multi-dimensional nature, there is no consensus on which domains are most important or should be included [149]. Patient satisfaction is sometimes treated as an outcome measure (i.e. satisfaction with health status after treatment) and sometimes as a process measure (i.e. satisfaction with the way care was provided) [125]. Four variables are reflected in the ratings of satisfaction: personal preferences of patients, patients' expectations, response tendencies due to personal characteristics, and the quality of the care received [150,151,152].

For many years, health care providers have been measuring patient satisfaction, but such efforts have had limited impacts [147,153]. Many researchers now believe that the modern health care complexities and the diversity of patients' expectations and experiences cannot be effectively evaluated by simply asking general ratings of satisfaction questions [125,144,140,142]. Global satisfaction ratings such as "How satisfied were you with the care you received?" can be misleading if there is no opportunity for patients to comment on their care in more detail. Kalucy *et al.* [154] summarize the problems associated with satisfaction studies as: the lack of universal definition of the term satisfaction; a disinclination of patients to be critical because of not wanting to jeopardize their treatment; satisfaction being determined largely by factors other than the actual health care individuals receive; and findings from satisfaction surveys being non-specific.

Because of the aforementioned problems, patient experience has begun replacing patient satisfaction as a tool for measuring the quality of health care services from patients' perspective [122, 149,147]. Salisbury et al. [122] assert that patients' experiences provide a more discriminating measure of a health service's quality and performance than do questions about satisfaction. Instead of asking patients to rate their satisfaction using general evaluation categories such as excellent, very good, good, fair and poor; they are asked to report in detail about their experiences of a particular service, hospital episode, general practice, or a care provider [125]. Patients are asked to indicate whether or not certain processes or events occurred during a particular encounter, or over a specified period. The focus is on what occurred (experience) rather than an evaluation of what occurred (satisfaction) [153]. This user reported experience approach to eliciting feedback from patients is considered useful for helping providers determine what action to take to address quality problems [149]. For instance, knowing that 25% of patients in a satisfaction study rated waiting times as "fair" or "poor" does not give organizations a clear view of what they need to do to improve waiting experience. On the other hand, knowing the exact proportion of patients who said they had to wait for more than 2 hours before seeing a clinician, and monitoring trends over time, can be more actionable.

Leading patient-centered promoter organizations such as the Picker Institute Europe, the Health Foundation, and the Beryl Institute advocate the measurement of

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patient experience instead of patient satisfaction. Most validated measurement instruments (e.g. the Picker Patient Experience Questionnaire, the Hospital Consumer Assessment of Healthcare Providers and Systems survey instrument, etc.) are designed purposefully to assess patient experience, with only a few of the items evaluating patients' overall satisfaction with care. Results of overall ratings are often correlated with patients' care experiences [155]. The assumption is that patients' evaluation of their overall satisfaction is influenced by various aspects of their experiences, and knowing the relationship between experience and overall satisfaction will help in identifying those aspects of health care experiences which matter most to patients [156].

Thus, patient experience is not the same as patient satisfaction. Researchers therefore need to distinguish between studies measuring patient experience and those assessing satisfaction. Nevertheless, patient experience and patient satisfaction are related. Improving patients' experiences of care will translate into their overall satisfaction with a health care system [155].

Factors influencing patient care experiences

One of the steps to improving health care experience, and for that matter health care quality, is the understanding of the factors underlying patient experience of care. Patient experience in health care organizations is shaped by organizational and human factors interacting in dynamic and complex fashions [157]. These factors are classified into four levels: individual

interaction between patient and staff member, the level of the clinical micro-system, the institutional level, and the wider context [133].

Individual interaction between patient and staff is the most immediate level of experience for patients and their families [133]. Patient characteristics such as: age, gender, ethnicity, educational level, health status, expectation, disposition, social status, time since care and previous experience differentiate some patients from others [154]. Thus, the ability of individual staff members to respond sensitively to patients as individuals is very vital to improving their care experiences [157].

The level of the clinical micro-system, which may be a department, a ward, or a clinical pathway, is the immediate environment that shapes relationships and interactions between patients and care providers [158]. People working in health care organizations belong to at least two different teams: their peers (e.g. nurse, health assistants, general practitioners, consultants, and managers), and the multidisciplinary team in the clinical micro-system, unit or department [159]. Team factors such as: leadership, morale, communication, flexibility, team ethos, values and priorities have profound effects on the quality of relationships and communication between patients and health professionals [133].

At the institutional level, the actions and words of senior leaders (board members, senior executives, and senior clinicians) have a greater impact on patients' experiences.

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They shape how managers and staff behave towards each other, and towards patients and families. They also shape how employees feel about the services they provide and the organization [133]. An observation by the UK Healthcare Commission (2008) [184] revealed that failures in service quality are mostly associated with senior leaders failing to show interest in the experience of patients and staff, and failing to focus systematically on service quality. Shaller [160] also observed that health care organizations in the United States with a reputation for service excellence have a common success factor – senior leaders feel directly responsible for the fate of staff and patients and families, and take their role in determining the quality of care and patients' experiences seriously.

Factors associated with the wider context are often beyond the control of senior leaders. Organizational strategies and plans are directly affected by national priorities, the actions of health care regulators, the actions of performance managers in the wider system and the financial rules and regulations governing contracts [159,161]. Thus, if senior leaders are to run health care organizations that deliver high-quality patient care, it is fundamentally important for them to understand the wider context that helps quality to thrive [162,161].

Patient experience and health care quality: empirical evidence of association

A range of studies over the years has investigated the association between patient experience and health care quality. Evidence suggests that patients who have positive health care experiences have improved

outcomes, resulting in a more efficient health care system [163,142].

Research has consistently demonstrated that patient experience correlates with clinical quality processes and outcomes. For instance, presenting early lessons on engaging patients to improve ambulatory care in four communities participating in the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative, Roseman [164] observed that measuring and improving the patient experience was positively associated with clinical processes of care. Similarly, examining the relationship between clinical quality and patient experience using data from two established measures of quality in primary care in England, Llanwarne [165] found positive correlations between clinical summary scores and patient survey scores. In a prospective study of acute myocardial infarction (AMI) patients, Meterko [166] found that patient reports of better patient-centered hospital care were significantly associated with better survival one year following discharge for AMI treatment. Glickman [167] reported that higher patient ratings of hospitals were independently associated with lower hospital inpatient mortality rates. A review of over 306 US hospital referral regions showed that hospitals with lower patient experience scores tended to have lower technical quality measures [168]. Sqfran [169] found that better patient reported experiences, particularly trust in providers and belief that providers have a comprehensive “whole person” knowledge of them improved patients' adherence to provider advice.

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Other studies have focused on the impact of particular dimensions of patient experience on health care quality. Good communication with patients has been found to contribute positively to well-being and speedy recovery [170]. A 2009 meta-analysis of 127 studies assessing the link between patient treatment adherence and provider-patient communication found a 19% higher risk of non-adherence among patients whose providers communicated poorly, and significant improvements in adherence among patients whose providers took part in communication skills training [171]. Evidence from clinical studies shows that anxiety and fear delay healing [172,173]. Brousseau et al. [174] indicated that children whose parents reported longer waiting times for primary care visits were more likely to visit emergency departments for non-urgent reasons than those who reported shorter waiting times. Wennberg [168] found that patients who reported poor provider-patient relationship were three times more likely to voluntarily leave a physician's practice than patients who reported high quality relationship.

Patient experience is also associated with key financial indicators, including patient loyalty and retention, reduced medical malpractice risk, and increased employee satisfaction [134,175,176]. A 1992 study found that patients' perceptions of quality explained almost 30% of the variation in hospital financial performance [177].

A systematic review by Doyle, Lennox and Bell summarizes the link between patient experience and health care quality. The

authors reviewed 55 studies to establish evidence on the links between patient experience and clinical safety and effectiveness outcomes (e.g. mortality, adherence to treatment recommendations, and lower use of additional healthcare). High levels of positive patient experience were found to be associated with high levels of patient safety and clinical effectiveness across disease areas, study designs, and self-reported and objective outcomes. The authors concluded that patient experience should be regarded as "one of the central pillars of quality in health care" with dimensions of quality being examined together rather than in isolation [163].

Conclusion

Quality improvement in the health care industry is of great importance on all levels: financial, strategic and patient care. Improved quality outcomes are not, however delivered solely by health service providers [178,179]. It is increasingly being accepted that patients must be part of any meaningful solution to the challenges facing health care. Particularly, in the case of chronic diseases, care providers cannot achieve positive health outcomes without commitment and action from patients and their families. Having more knowledgeable and engaged patients making informed decisions about their care and managing their health would improve both the quality of care and health outcomes [180].

Developed health care systems are shifting from paternalistic to partnership models of care [76,180]. A number of strategies are available to actively involve patients in health care provision. These strategies can

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substantially contribute to the implementation of quality initiatives in practice. Patient-focused strategies are those that recognize patients' role as active participants in the process of care delivery [149]. As a guiding principle in quality improvement in health care, patient-centeredness has been demonstrated as a way to addressing the power inequality and the existing tensions in the relationship between health care professionals and patients [181]. It is regarded as the proper and respectful mode of care delivery [16].

Given the high-level political commitment to patient empowerment, and the increasing recognition that a high quality health service is the one organized around and responsive to the needs of the people using it [182], the area of patient-focused strategies is likely to receive even greater attention in the future. The research community therefore needs to explore various ways of using patient-focused interventions more effectively in quality improvement at both an individual and a collective level. Particularly, researchers should consider: 1) determining empirically, the association between the various models of chronic disease care and the outcomes of patient self-care interventions; and 2) exploring possible ways of developing global, generic frameworks of patient experience domains that could be prioritized in quality improvement programs. Policy makers also need to invest more in efforts to develop and improve the interpersonal skills of health professionals so they could involve patients better and more effectively in routine clinical care.

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